

How We Can All Talk About Death

There's no one-size-fits-all approach

June 17, 2019 Sarah C. Hull, MD

End-of-life care is often fraught with uncertainty, guilt, and suboptimal communication. As a *cardiologist who specializes in treating cancer patients with heart problems*, I have significant experience in addressing life-threatening and terminal conditions and have had many conversations about death in a variety of contexts. And as an ethicist, I know the medical profession can and must do far better in guiding patients toward what has been termed a "good death" in which suffering is alleviated and dignity is preserved. *The involvement of palliative care specialists, who administer care focused on comfort rather than cure, can often help us to achieve that end. However, I was dismayed to read the thinly veiled tropes portraying doctors as clueless and callous under the guise of patient advocacy in a recent New York Times op-ed, "How to Make Doctors Think About Death," by Theresa Brown.*

While I wholeheartedly agree with her premise that better communication and willingness to involve palliative care when appropriate are essential in order to improve end-of-life care, *her conclusion that guidelines are the answer falls short of addressing the root causes of the problem.* Furthermore, nurses do not have a monopoly on sensitivity and compassion, and her painting physicians with such a broadly negative brush does a disservice to our profession and more importantly to our patients.

As she correctly notes, lack of communication is often due to lack of time. Our culture has a ruthless obsession with efficiency, which in principle seems laudable, but in practice leads to the conflation of efficiency (doing the best work possible in the least amount of time) with rapidity (doing as much as possible without regard to quality in the least amount of time). *Doctors often face enormous pressure to see more and more patients in less and less time, and when pushed too far this sends us the implicit message that productivity is valued above quality and compassion.* This dynamic is one of the reasons that physician burnout has become such a widespread phenomenon.

Another barrier to delivering adequate end-of-life care is a culture of rescue and litigation. Ms. Brown makes numerous references to *the trope of "cavalry," physicians pushing patients toward overly aggressive therapy when it is no longer appropriate, which certainly does happen and should indeed be discouraged.* However, far more frequently I see physicians in the opposite situation, trying to dissuade patients and families from insisting upon invasive measures when their hopes for cure are unrealistically optimistic despite numerous attempts to convey a more accurate picture. *If physicians do not acquiesce to certain requests or demands, we may be threatened with lawsuits, while typically nurses have the luxury not to worry about this. Guidelines that "empower nurses ... irrespective of physicians" by prompting automatic palliative care consultation, for example, can backfire and only cause patients and families to view their medical team with distrust.* In particular, marginalized communities who have historically been undertreated by the medical community may be especially and understandably reluctant regarding palliative care and need to be approached with sensitivity given the context of past injustices. Sometimes family members know their loved one is dying but they feel guilty about letting them go without a fight, and offering a few days of reasonably aggressive treatment before transitioning to comfort care allows them to say goodbye with more closure.

On the contrary, *if a palliative care specialist shows up before patients and families are ready to meet with one, they may feel like the medical team is "giving up" on them. Complicating matters further, many different specialists may be consulting on a single patient's case, and without clear communication among them and identifying the primary doctor responsible for keeping a patient and family informed, further confusion and mistrust can ensue.* To be clear, if physicians made more time during regular office visits to discuss goals and objectives before the very end of life, many unnecessary intensive care unit (ICU) admissions could be avoided. *On the other hand, progression to end-stage disease is rarely linear and can be challenging to predict. Regardless, pushing patients toward palliative care before they feel ready violates the principles of autonomy and non-maleficence just as much as pushing them away from it does.*

As a wise mentor once told me, precision medicine does not only apply to genes. *When caring for patients, we need to remember that our actions should not be to promote a physician's agenda or a nurse's agenda, but rather to ensure that the patient's agenda is respected above all. We can do this best not by implementing one-size-fits-all guidelines or making power plays,* but rather by providing the time and space for better communication and listening to each other, *working together to develop an individualized plan of care that honors each patient's values and wishes.*

Sarah C. Hull, MD, MBE (Master of Bioethics), is a board-certified cardiologist whose clinical practice includes general cardiology, echocardiography, and cardio-oncology at Yale-New Haven Hospital. She also teaches cardiology and medical ethics at Yale School of Medicine.